

The National Survey of Children with Special Health Care Needs Summary Report



A comprehensive statewide need assessment of children with
special health care needs and their families in North Dakota

Conducted by the Children's Special Health Services Unit
Medical Services Division, ND Department of Human Services

January, 2005

The National Survey of Children with Special Health Care Needs Summary Report

Contents

Background	Page 3
Methods	Page 3
Purpose	Page 4
Identification	Page 4
Questionnaire Content	Page 5
Demographic Characteristics	Page 5
Survey Results	
Care Within a Medical Home	Page 6
Adequate Insurance	Page 7
Participation in Decision-Making	Page 8
System Organization	Page 9
Transition	Page 9
Service Utilization	Page 10
Impact on Children	Page 11
Impact on Families	
Financial Impacts	Page 11
Employment Impacts	Page 12
Other Impacts	Page 13
Service Needs and Access	Page 13

North Dakota Department of Human Services
Medical Services Division
Children's Special Health Services Unit
600 East Boulevard Avenue – Dept. 325
Bismarck, ND 58505-0269
Phone: (701) 328-2436
Fax: (701) 328-1645
Toll-free: 1-800-755-2714
Email: dhscshs@state.nd.us
www.state.nd.us/humanservices

Background

The Maternal and Child Health Bureau (MCHB) in the Health Resources and Services Administration in the US Department of Health and Human Services defines children with special health care needs (CSHCN) as “those children who have or are at risk for chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.”

A National Survey of CSHCNs was commissioned by MCHB and conducted by the National Center for Health Statistics at the Centers for Disease Control and Prevention (CDC) in 2000. The survey used population-based survey methodology from the State and Local Area Integrated Telephone Survey (SLAITS). This survey mechanism was developed by CDC to measure and monitor changes in health, health care, and well-being at state and local levels. The SLAITS sampling frame is shared with the National Immunization Survey.

Methods

The National Survey of Children with Special Health Care Needs was conducted between October of 2000 and April 2002 using a random-digit-dial telephone survey with computer assisted telephone interviews. Household interviews were conducted and the survey contained a screener to identify children under age 18 in the household for chronic health conditions. A detailed interview was then completed for one randomly selected child with special health care needs in the household. Adjustments were made to account for households without telephones. Additional information, including survey technical documentation, can be found at http://www.cdc.gov/nchs/data/series/sr_01/sr01_041.pdf.

More than 3000 households were screened to identify at least 750 CSHCNs in each state. The National Survey of CSHCNs was the first ever effort to identify the number and percentage of children who were considered to have a special health care need in the United States and for each state. Interviews were conducted with nearly 4000 households in ND involving more than 7,500 children. Based on responses to screener questions, 12.4 % of children in ND were found to

have a special health care, need slightly less than the percentage nationally (12.8%). Accounting for the estimated child population under age 18, about 19,500 children in ND are thought to have special health care need.

Purpose

The primary goal of the National CSHCN Survey was to assess the prevalence and impact of special health care needs among children and their families. This was assessed by focusing questionnaire content on the following themes:

- Health and functional status
- Health insurance and adequacy
- Access and utilization
- Care coordination
- Satisfaction with care
- Impact on families

Identification

A CSHCN screener in the household survey was used to identify children with special health care needs. Children were determined to have a special health care need if they met any of the following criteria:

- They need or use medicine prescribed by doctor
- They need or use more medical care, mental health, or educational services than is usual for most children
- They are limited or prevented in their ability to do things
- They need or get special therapy
- They need or get treatment for an emotional, developmental, or behavioral problem
- Their condition is expected to last more than a year

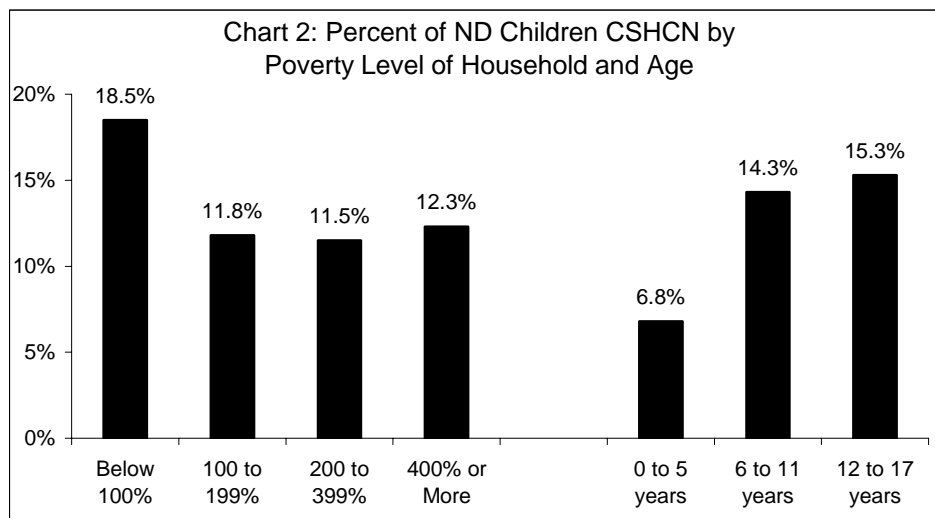
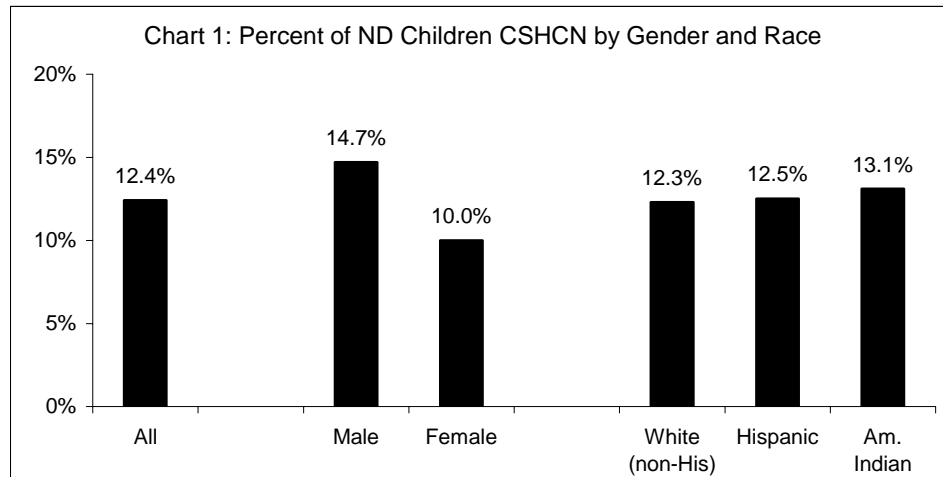
Questionnaire Content

Prior to the survey, the MCHB launched an initiative entitled *Achieving and Measuring Success: A National Agenda for Children with Special Health Care Needs*. The agenda calls for the development of systems of care for CSHCN that are family-centered, community-based, coordinated and culturally competent. Six critical indicators for measuring success were identified. The six core outcomes to be achieved were:

1. All children with special health care needs will receive coordinated ongoing comprehensive care within a medical home.
2. All families of children with special health care needs will have adequate private and/or public insurance to pay for the services they need.
3. All children will be screened early and continuously for special health care needs.
4. Services for children with special health care needs and their families will be organized in ways that families can use them easily.
5. Families of children with special health care needs will partner in decision making at all levels, and will be satisfied with the services they receive.
6. All youth with special health care needs will receive the services necessary to make appropriate transitions to adult life.

Demographic Characteristics

The National Survey of CSHCNs collected demographic information for the children identified as CSHCN in each state. In North Dakota, males were more likely to be identified as having a special health care need than females and minority children were slightly more likely to be identified as having a special health care need than White children (Chart 1). Children living in households with incomes below 100% of the federal poverty level were more likely to be CSHCN than children living in households with higher incomes and CSHCN tended to be older (Chart 2) likely due to the nature of the screener questionnaire.



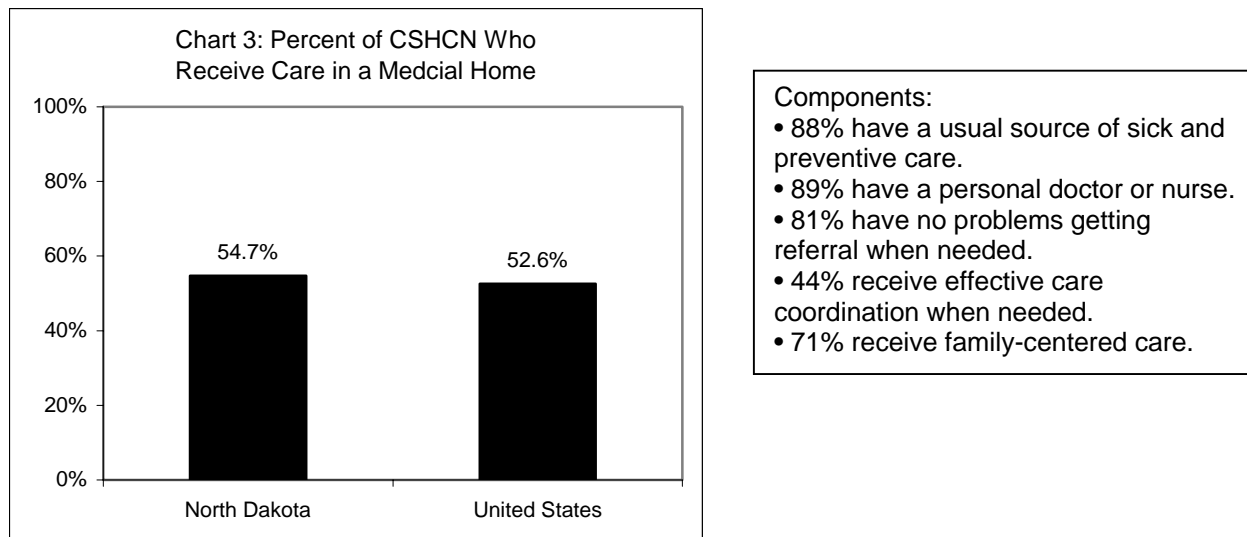
Results

Detailed interviews were conducted with the families of 746 children with special health care needs in North Dakota. In the National CSHCN Survey, several questions were combined in order to measure the components of each core outcome. Responses from the separate questions were weighted to calculate state and national baseline data for each outcome measure. The following summary compares results for the 746 ND CSHCNs to results for children with special health care needs nationally.

Care Within a Medical Home

Eighty-eight percent of ND families of CSHCN reported their child with special health care needs had a usual source of both sick and preventive care. A similar percentage indicated their child had a personal doctor or nurse. Eighty-one percent said their child had no problems obtaining a referral when needed but only forty-four percent felt they received effective care coordination when they needed it. Care coordination was measured by whether the child received professional care coordination and how well families thought their child's doctors communicated with each other and with other programs.

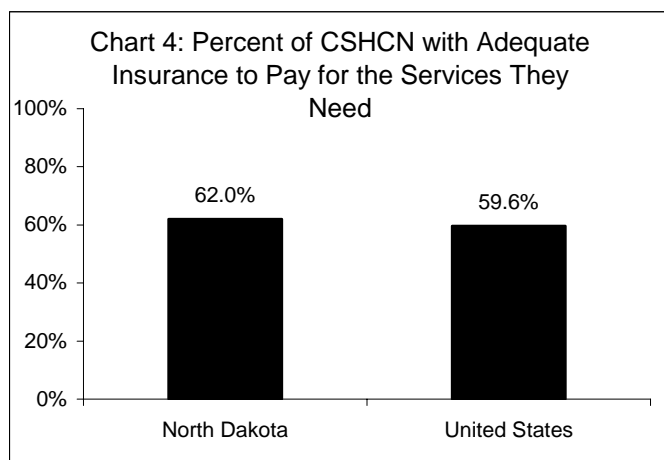
Seventy-one percent felt their child received family-centered care which was measured by the degree to which families felt their child's doctor spent enough time and listened carefully to them, were sensitive to their values and customs, provided needed information, and make them feel like a partner. Overall, when the component questions were weighted, fifty-five percent of ND families felt their child with special health care needs received coordinated, ongoing, comprehensive care within a medical home compared to fifty-three percent nationally. (Chart 3)



Adequate Insurance

Assessment of insurance status among CSHCN was based on questions related to their coverage status and adequacy of the coverage – how well the insurance paid for the services needed by the

child with special health care needs. Ninety-five percent of ND CSHCNs had a source of private or public coverage at the time of the interview and eight-seven percent reported having no gaps in coverage during the last year. Eighty-nine percent of parents of CSHCN said their insurance usually or always met their child's needs. Overall, sixty-two percent of ND families of CSHCN were determined to have adequate private or public insurance to pay for the services their child needed, compared to sixty percent nationally. (Chart 4)

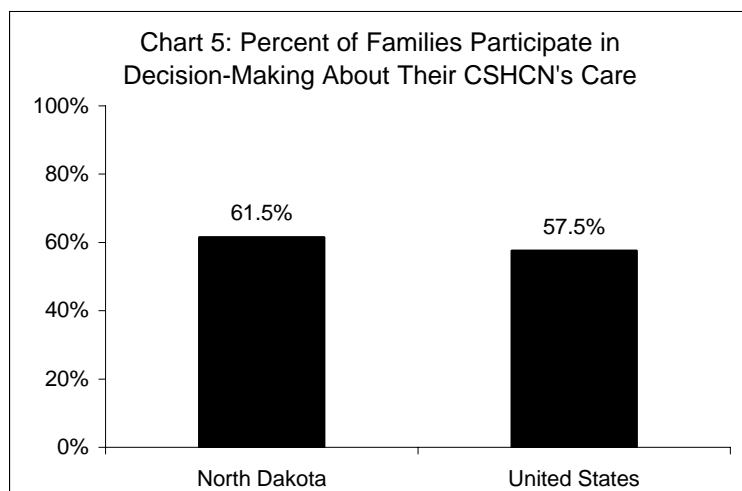


Components:

- 95% of child have public or private insurance.
- 87% had no gaps in coverage during the year.
- 89% feel Insurance usually or always meets child's needs.
- 72% feel costs not covered are reasonable.
- 92% have insurance that permits child to see needed providers.

Partnership in Decision-making

Eighty-six percent of ND families with CSHCN indicated their child's doctor usually or always made the family feel like a partner and 64 percent of families reported they were very satisfied with the services their child received. Overall, sixty-two percent of ND families felt they were partners in decision-making and were satisfied with the services they received, compared to fifty-eight percent nationally. (Chart 5)

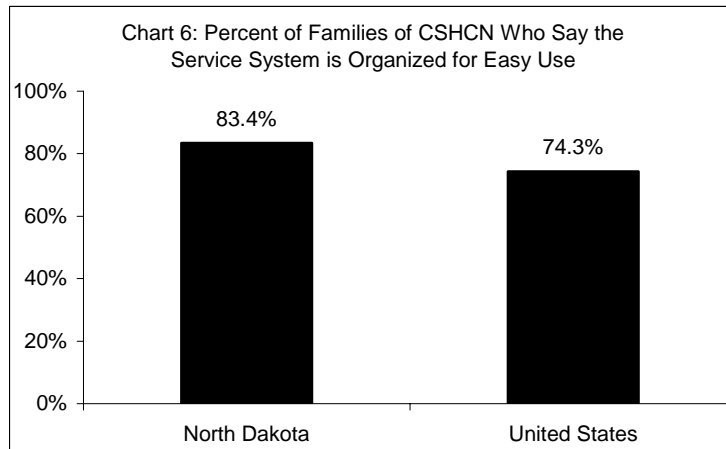


Components:

- 86% say doctors make the family feel like a partner.
- 64% of families are satisfied with services received.

System Organization

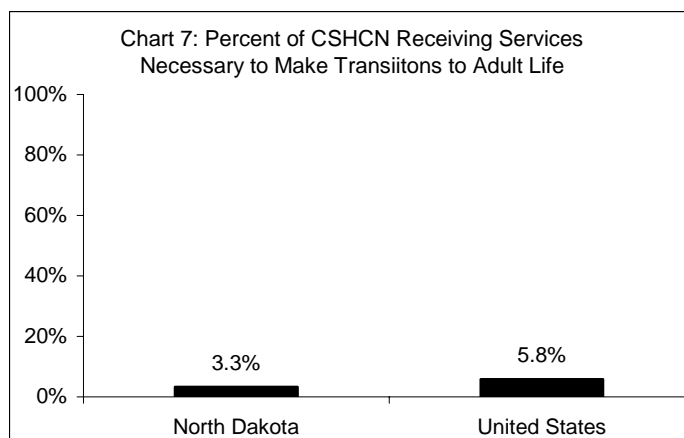
Eighty-three percent of ND respondents indicated that community-based service systems were usually or always organized so they can use them easily, compared to seventy-four percent nationally (Chart 6).



Component:
• 83% feel services are usually or always organized for easy use.

Transition

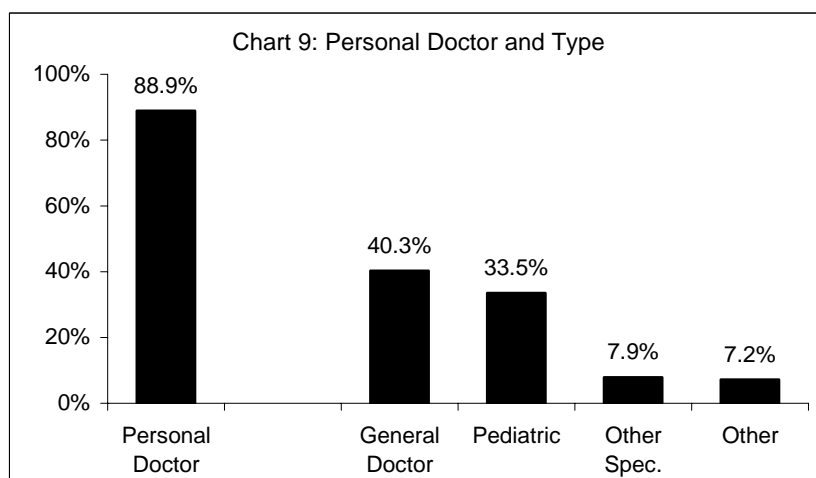
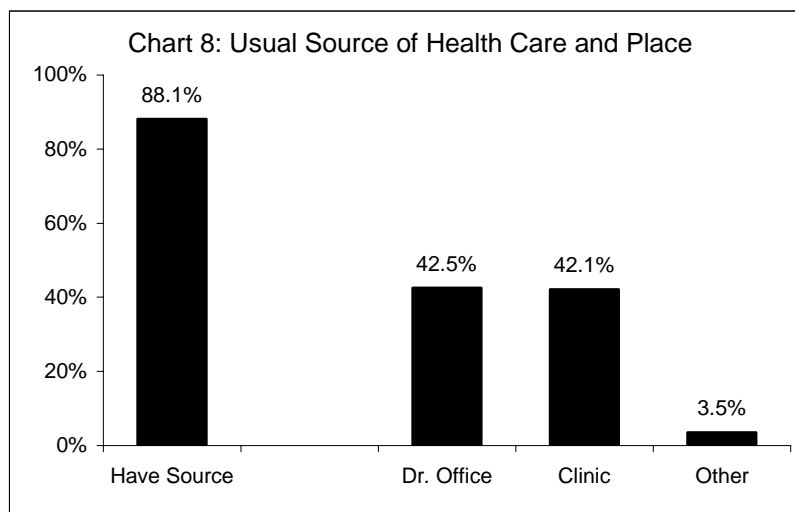
Thirteen percent of ND youth or young adults had received guidance and support in the transition to adult life, including adult health care, work and independence. More than half (55 percent) reported doctors having talked about changing needs but only one-third (34 percent) of doctors had discussed a shift to an adult provider. Only twenty-nine percent had received vocational or career training. Overall, just three percent of ND youth have received the services to make transitions to adult life, compared to six percent nationally. (Chart 7)



Components:
• 13% of children have received guidance and support in the transition to adulthood.
• 55% have had doctors talk to them about changing needs.
• 58% of children have a plan for addressing changing needs.
• 34% report doctors have discussed shift to adult provider.

Service Utilization

Eighty-eight percent of ND CSHCN indicated they had a usual source or place of health care and eighty-nine percent reported they had a personal doctor or nurse. Of the children who had a usual source of health care, most indicated either a doctors office or a clinic or health center was the kind of place they usually go for care (Chart 8). Forty percent of ND children with a personal doctor or nurse said a general doctor was their kind of personal care provider and eight percent said it was another specialist. Just over one-third (34 percent) of ND CSHCN indicated a pediatrician was their kind of personal care provider. (Chart 9).



Impact on Children

Several questions were asked to assess the impact of special health care needs on affected children. Thirteen percent of ND respondents reported their child's condition affected their ability a great deal and more than half said it affected them to some degree (Chart 10). Only four percent of respondents said their child's health care needs change all the time and twenty-eight percent said they change only once in a while. More than two-thirds indicated their child's health care needs are usually stable (Chart 11).

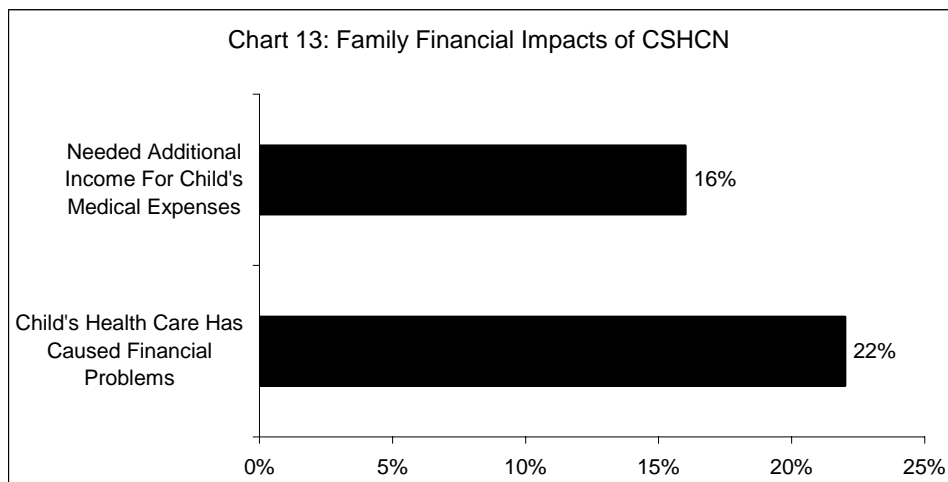
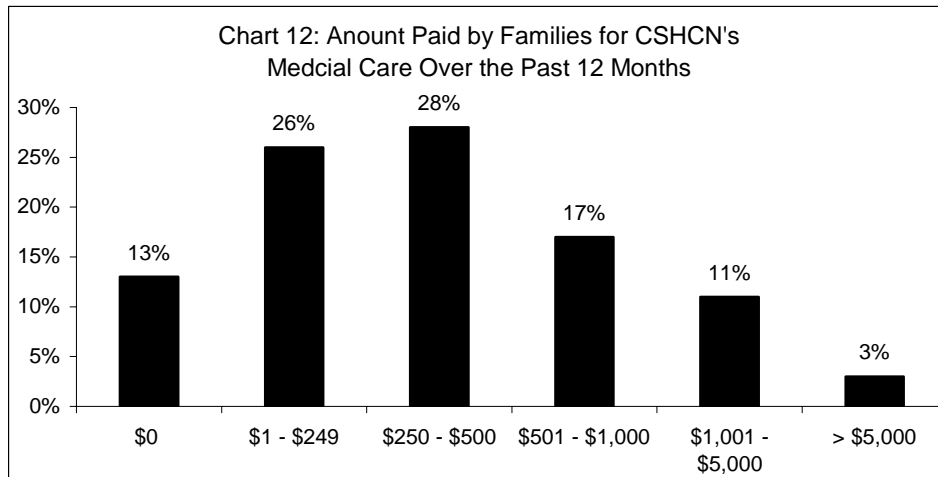
Chart 10: How Severely Condition Has Affected Child's Ability		
	ND	US
A Great Deal	13%	17%
Some	51%	45%
Very Little	35%	37%

Chart 11: Best Description of Child's Health Care Needs		
	ND	US
Change All the Time	4%	6%
Change Only Once In A While	28%	29%
Are Usually Stable	68%	65%

North Dakota children with special health care needs, on average, missed fewer school days than CSHCN nationally. Sixty percent of ND CSHCN missed fewer than five school days during the past year compared to fifty percent nationally. Less than ten percent of ND CSHCN missed more than ten school days due to illness or injury.

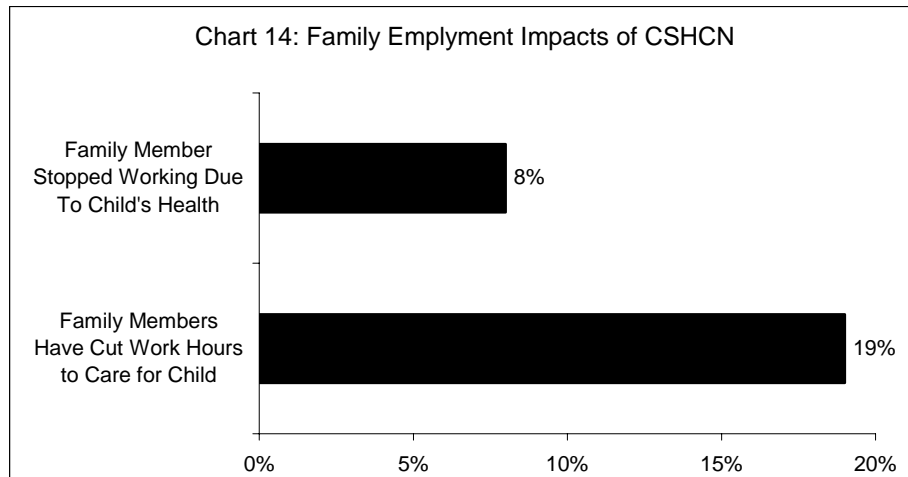
Financial Impact on Families

Thirty percent of North Dakota families with CSHCN spent more than \$500 on their child's medical care during the past 12 months and another 28 percent spent between \$250 and \$500. One in seven families (14%) spent more than \$1000 on their child's medical care during the past year. (Chart 12) Twenty-two percent of ND families with CSHCN indicated their child's health problems have caused financial problems for them and sixteen percent of ND families said they needed additional income for their child's medical expenses (Chart 13).



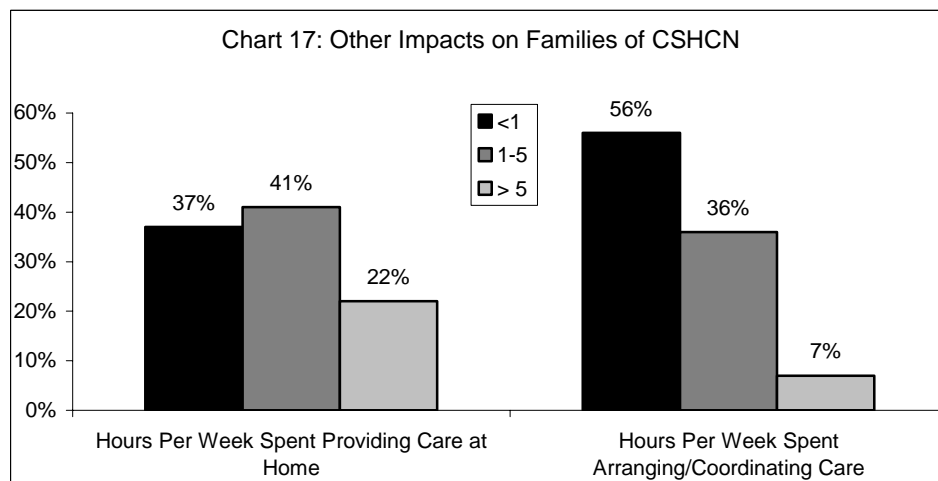
Employment Impact on Families

Nineteen percent of ND families reported that have cut work hours to care for their child with special health care needs and eight percent of ND families had a family member who stopped working due to their CSHCNs health. (Chart 14).



Other Impacts

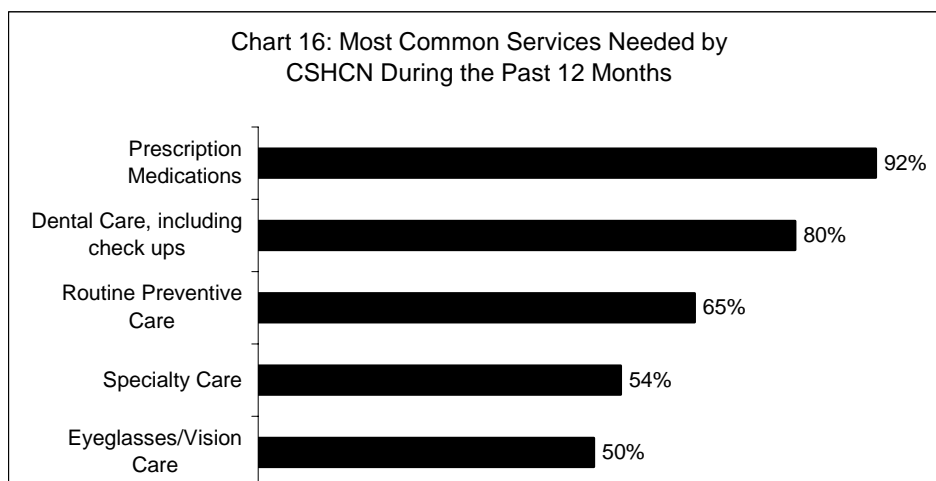
More than half of ND families with CSHCN said they provide health care at home for their child. Sixteen percent of those reported spending more than ten hours per week providing care at home for their child. Thirty-six percent of ND families with CSHCN spent between one and five hours per week arranging or coordinating care for their child. An additional seven percent said they spent six or more hours per week arranging or coordinating this care (Chart 15)



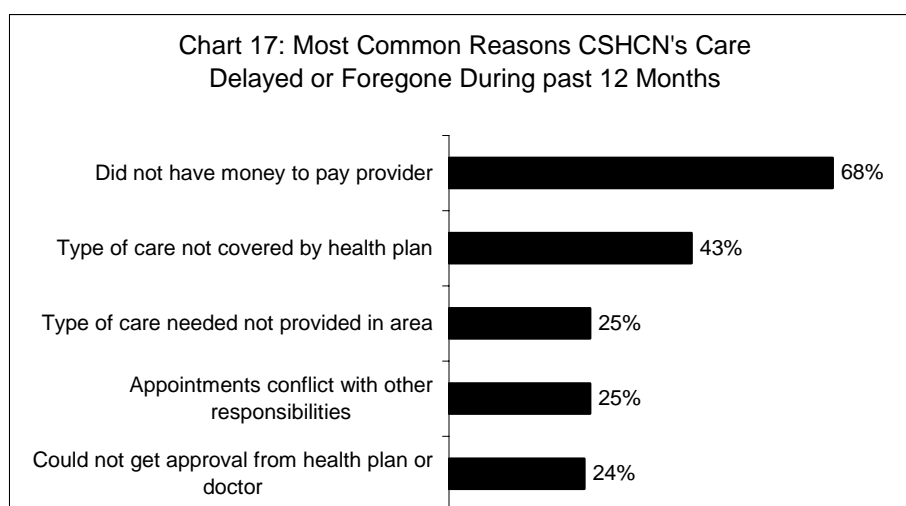
Service Needs and Access

Survey respondents were provided a list of health care services and were asked to indicate if their child needed the services in the past twelve months. More than ninety percent of families

indicated their CSHCN needed prescription medications and four in five needed dental care, including check ups. More than half (54%) needed specialty medical care services (Chart 16).



Only eight percent of families indicated care for their CSHCN had been delayed or foregone at any time during the past twelve months. Of those whose care was delayed or foregone, not having money to pay the provider and the type of care their child needed was not covered by their health plan were the two most common reasons given for their child not getting care. About one-fourth listed either the type of care their child needed was not provided in their area, they could not get approval from their health plan or doctor, or their child's appointments conflicted with other home or work responsibilities as reasons for delaying or not getting care (Chart 17).



For more information contact:

North Dakota Department of Human Services
Medical Services Division
Children's Special Health Services Unit
600 East Boulevard Avenue – Dept. 325
Bismarck, ND 58505-0269
Phone: (701) 328-2436
Fax: (701) 328-1645
Toll-free: 1-800-755-2714
Email: dhscshs@state.nd.us
www.state.nd.us/humanservices